Chronic centralized pain syndromes: A rheumatologist’s perspective

Chronic centralized pain syndromes are extremely important, common, and vexing for both patients and clinicians. In this issue of the Journal, Volcheck et al present a framework that I believe is useful for understanding chronic centralized pain and for developing an actionable treatment plan for patients.

It has been estimated that more than 30% of primary care visits relate to the need to address painful conditions. I would guess that a significant number of those patients have chronic generalized pain not explained by a specific injury or demonstrable inflammation, and that they are ultimately diagnosed with fibromyalgia, the prototypic central sensitization pain syndrome. While there are regional and individual physician differences in practice behavior, many of these patients are referred to rheumatologists despite the absence of a clinically demonstrated and relevant inflammatory or autoimmune pathobiology.

For decades there have been discussions within the rheumatologic community, including live debate at our annual rheumatology scientific meeting, whether such referral is appropriate or ultimately of net benefit. I would characterize this debate as ongoing and overlapping with similar debate regarding referral of patients with chronic fatigue syndrome (myalgic encephalomyelitis) and now with “long COVID.” Given the high prevalence of these syndromes and the limited number of rheumatologists, many rheumatology practices have declined to accept for consultation or provide ongoing chronic care for patients with these diagnoses. Our clinic has not made it a rule to do that, which has translated into some days scheduled with at least half of my patients experiencing fibromyalgia or a related syndrome as their primary concern, with the current buzzword for referral being “suspected autoimmune disease.” As a result, I frequently struggle to fit patients with joint or urgent organ-threatening inflammatory issues into my schedule in a timely manner.

In writing the above, I do not wish to minimize in any way the significant impact of chronic pain and fatigue on the lives of patients with fibromyalgia and related disorders. As Volcheck et al discuss in this issue of the Journal, patient and physician education are essential in the management of patients with chronic centralized pain. I believe that too often there is a lack of understanding and acceptance of the concepts of central sensitization. Often, there is a lack of comfort in making and accepting the diagnosis. The patient is questioning how they can have so much pain and if this is all in their head, and the clinician is examining what they are missing, and how to be sure that this is not an autoimmune disorder heralded by pain and fatigue. It is this last concern that leads to the ordering of a panoply of serologic immunologic tests, especially antinuclear antibody (ANA), despite the absence of any clinical or laboratory features truly suggestive of lupus or related conditions. Several studies indicate the strikingly limited (virtually zero) utility of checking ANA in patients with symptoms limited to generalized pain and fatigue, especially when careful examination of skin, lymph nodes, muscle strength, and joints and a complete blood count, comprehensive metabolic panel, and thyroid-stimulating hormone are unrevealing. Yet the practice of ANA testing remains prevalent. If results are weakly positive, which may be present in about 25% of the healthy population, patients are diagnosed with an autoimmune disorder and are referred.
to specialists for evaluation, a practice almost guaranteed to increase patient stress and their expectation for pharmacotherapy.

Despite several direct-to-consumer advertising campaigns, the benefits of pharmacotherapy for patients with fibromyalgia and central sensitization syndromes are modest at best. There are benefits for treating patients with coexistent significant anxiety, depression, bipolar disorders, or specific sleep disorders, and patients should be evaluated for these conditions. But patients can usually be directly diagnosed with fibromyalgia, with or without these associated conditions. Fibromyalgia is not just a “wastebasket” diagnosis of exclusion or frustration.

While it is always important to keep an open mind and avoid the clinical sin of premature closure, making the diagnosis with confidence is important. Reassurance and behavioral treatment approaches can be provided, and previous patient experiences and symptoms can be explained and even described by the clinician without hearing them from the patient. For example, on “less-bad” days, patients try to accomplish many tasks that they could not do the preceding few days and then end up almost disabled by pain or fatigue for the next several days, by the development of intolerance to touch, strong odors, or noises, by dyspareunia (in women), and by the sensation of pain from frequent culture-negative urinary tract infections (interstitial cystitis). Recognition of these chronic central pain syndromes is also important when addressing other comorbidities, as the presence of significant fibromyalgia may reduce the perceived benefits following joint replacement or spine surgery.

While I have significant reservations about the current “narcotics for no one” approach to pain management (speaking from personal experience after undergoing surgically treated renal colic), opioids should be avidly avoided in the treatment of fibromyalgia and related central pain syndromes.